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APOIO E CAPACITAÇÃO DOS CUIDADORES FAMILIARES: PROGRAMA DE INTERVENÇÃO DE ENFERMAGEM
SUPPORT AND TRAINING OF FAMILY CAREGIVERS: NURSING INTERVENTION PROGRAM
APOYO Y CAPACITACIÓN DE LOS CUIDADORES FAMILIARES: PROGRAMA DE INTERVENCIÓN DE ENFERMERÍA

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RESUMO

Introdução: Com o envelhecimento populacional e melhoria dos cuidados de saúde, constata-se um aumento de pessoas dependentes que requerem maior apoio para a satisfação das suas necessidades. O cuidador familiar (CF) é fundamental para garantir a continuidade de cuidados, apesar de ser um processo desgastante e com consequências na saúde. Um programa de intervenção de enfermagem (PIE), devidamente estruturado, revela-se importante neste contexto.

Objetivo: Desenvolver e implementar um PIE de apoio e capacitação aos CF de pessoas dependentes.

Métodos: Foi realizada uma revisão integrativa da literatura (RIL) que permitiu evidenciar as principais necessidades cuidadores. Depois foi estruturado um PIE, nos domínios do apoio emocional e instrumental, validado por peritos da área, com recurso à técnica de Delphi. Este foi implementado e avaliado, com recurso a um estudo quase experimental, com avaliação pré e pós intervenção.

Resultados: Da RIL evidenciaram-se 21 artigos, que destacaram as principais necessidades manifestadas pelos CF. Da técnica de Delphi obteve-se um PIE com 93 intervenções de enfermagem. Da sua implementação, obteve-se uma melhoria geral do estado de saúde do CF, uma diminuição da sobrecarga manifestada e um maior recurso a estratégias de *coping*.

Conclusões: Intervenções de Enfermagem estruturadas e contextualizadas, direcionadas para o apoio e capacitação dos CF, são facilitadoras da transição para este papel, com impacto na sua saúde e nos cuidados prestados.

Palavras Chave: Cuidadores Familiares; Programa de Intervenção; Transição; Necessidades; Dependência

ABSTRACT

Introduction: With an aging population and improvements in health care, there is an increase in the number of dependents who require more support to meet their needs. Family caregivers (FC) are essential to guarantee continuity of care, even though it is an exhausting process with consequences for their health. A properly structured nursing intervention program (NIP) is shown to be important in this context.

Objective: To develop and implement a NIP to support and train the FC of dependent people.

Methods: An integrative literature review (ILR) was conducted to identify the main caregiver needs. Afterwards, a NIP was structured in the areas of emotional and instrumental support. It was then validated by experts in the field using the Delphi technique. This was implemented and evaluated, using a quasi-experimental study, with a pre and post intervention evaluation.

Results: From the ILR, 21 articles were stood out for highlighting the main needs manifested by FC. Through the Delphi technique an NIP was obtained with 93 nursing interventions. Its implementation led to a general improvement in the FC's state of health, a reduction of the overload manifested and a greater use of coping strategies.

Conclusions: Structured and contextualized nursing interventions, directed to supporting and empowering FC, facilitate the transition to this role with an impact on their health and the care provided.

Keywords: Family Caregivers; Intervention Programme; Transition; Needs; Dependency

RESUMEN

Introducción: Con el envejecimiento de la población y la mejora de la atención sanitaria, se constata un aumento de las personas dependientes que requieren mayor apoyo para satisfacer sus necesidades. El cuidador familiar (CF) es fundamental para garantizar la continuidad de cuidados, a pesar de ser un proceso desgastante y con consecuencias en la salud. Un programa de intervención de enfermería (PIE), debidamente estructurado, resulta importante en este contexto.

Objetivo: Desarrollar e implementar un PIE de apoyo y capacitación a los CF de personas dependientes.

Métodos: Se realizó una revisión integrativa de la literatura (RIL) que permitió evidenciar las principales necesidades cuidadores. Después se estructuró un PIE, en los ámbitos del apoyo emocional e instrumental, validado por expertos del área, con recurso a la técnica de Delphi. Este fue implementado y evaluado, con recurso a un estudio casi experimental, con evaluación pre y post intervención.

Resultados: De la RIL se evidenció 21 artículos, que destacaron las principales necesidades manifestadas por los CF. De la técnica de Delphi se obtuvo un PIE con 93 intervenciones de enfermería. De su implementación, se obtuvo una mejora general del estado de salud del CF, una disminución de la sobrecarga manifestada y un mayor recurso a estrategias de *coping*.

Conclusiones: Intervenciones de Enfermería estructuradas y contextualizadas, dirigidas al apoyo y capacitación de los CF, son facilitadoras de la transición a este papel, con impacto en su salud y en los cuidados prestados.

Palabras Clave: Cuidadores Familiares; Programa de Intervención; Transición; Necesidades; Dependencia

INTRODUCTION

The results of the 2011 census (INE, 2012) confirm that population is aging. This results from a combination of factors, including the increase in average life expectancy, the result of improved health care, as well as the increased incidence of chronic diseases and/or those that lead to disability. The loss of capabilities occurs as a normal consequence of the life cycle and the aging process and the onset of chronic and disabling diseases lead to loss of independence and increased dependency. This leads to needing the support of others to satisfy basic human needs and maintain quality of life (Sequeira, 2010).

Continuity of support and care is essential for people who are dependent. Informal caregivers play a key role in providing most partial or complete care to the dependent person, being responsible to organize it, without receiving any compensation for their service (Marques, 2007). These caregivers are mostly family members and should therefore be designated family caregivers (FC) (Sarmiento, Pinto & Monteiro, 2010).

Since the informal care exercised by FC is increasingly important in today's society, it is worth investigating what the care process means in this area because the health of these caregivers will potentially be affected (André, Cunha & Rodrigues, 2010). The transition to the role of the situational type FC (Meleis, 2010) associated with continuous care means they face a number of challenges and obstacles, which can lead to an increased burden in different areas, as well as often negative consequences for their health.

Health professionals, including nurses, play an important role in the support available to FC and their capacity to care for their dependent relative (DR), with theoretical and practical knowledge to enable them to provide better quality of care and fewer repercussions for themselves (Petronilho, 2007).

A set of structured, contextualized interventions directed to the needs highlighted by FC, organized as a nursing intervention programme (NIP) was shown to be a useful tool in nurses' work, facilitating the transition experienced by caregivers.

Under these assumptions, the objective of this work is to develop an NIP and implement it with FC of dependent people in the context of the home to support and empower them.

1. THEORETICAL FRAMEWORK

The concepts dependence, loss of autonomy and needs in self-care are closely interlinked and increase significantly with aging. Dependence can be defined as the state in which the person, due to physical or intellectual limitations, needs help to meet their most basic day-to-day needs (Nogueira, 2009). From this perspective, the dependent person needs the support of others to accomplish activities that allow them to maintain life, health and well-being. Self-care (Orem, 2001) is a concept associated with autonomy and independence, which implies health and well-being and may be innate or learned (Petronilho, 2012).

The family plays roles in various areas in psychobiological, socio-cultural, educational and economic terms. It is within the family context that the dependent person initially seeks the support they need (Sarmiento et al, 2010), which is essential for their balance and well-being.

Caring is from Collière's perspective (2003), the activities carried out in order to maintain someone's well-being and quality of life, assisting them in their needs, to enable a favourable level of autonomy. The FC thus emerge, as members of the family, performing this function without any remuneration, being responsible for providing most of the care needed, taking responsibility for the whole process (Martins, 2006; Marques, 2007). There are different factors that lead the family to assume the role of caregivers of the dependent person, in particular a close relationship with their family, kinship, cohabitation and satisfying a desire, both on the part of those who provide the care as those who receive it.

The transition to the role of FC, a situational type (Meleis, 2010) is a multidimensional, complex and unique process, which brings about a set of specific needs that require support to be met.

The process of care is complex and dynamic, requiring a continuous effort at the cognitive, emotional and physical levels, which often goes unrecognized and is inadequately rewarded. When prolonged over time, its negative effects emerge bringing complications and consequences not only at the personal level, but also within the family. It can cause significant changes to the family's internal dynamics and, consequently, the society in general. So caring for a dependent person results in increased stress for the caregiver, overload in different areas, such as psychological, physical and economic (not only the high costs associated with the care provided, but also the enormous difficulty in reconciling this new role with being a worker with a paid job). It can also lead to increased incidence of disease, significant changes to the relationships in the family and social isolation, with the deterioration of most social roles played by this person up to then (Figueiredo, 2007; Imaginário, 2008; Marques, 2007; Martins, 2006; Pereira, 2013; Sequeira, 2010).

In this context, nurses are key actors and facilitators in the transition process, whether going from an independent situation to a situation of dependency, or in assuming new roles, as in the case of caregivers, providing support and empowering the FC in the new role. Thus, the nursing intervention, if properly structured and based on an adjusted and contextualized policy program can be a gain, not only for the FC, but also for the dependent person.

2. METHODS

In order to achieve our aims, this work was divided into several phases.

The aim of the first phase was to identify the main needs as indicated by FC of the dependent person, especially in transitioning to this role, based on by scientific evidence, so that an integrative literature review (ILR) was conducted.

In this context, a literature search was conducted between the months of April and June 2011, using national and international electronic databases in health care, including EBSCO and B-on, with recourse to specific search engines. The following descriptors were used in the research: *Caregiver; Family Caregivers; Needs; Dependent*, using the Boolean characters *and* and *or* to combine them. Works published between January 2000 and June 2011 were selected; English was the language of choice. In order to facilitate the survey, inclusion and exclusion criteria were chosen, thereby generating a rigorous work (see Table 1).

Table 1 - Inclusion and exclusion criteria from the integrative literature review

Inclusion Criteria (Title/Content)	Exclusion Criteria (Title/Content)
Family Caregivers	Formal Caregivers
Aged over 18	Aged under 18
Care provided at home	Institutional care provided
Care provided to dependent people in self-care	Other topics
Needs of family caregivers	

Initially, articles were selected based on the title, followed by reading the abstract and then by the full text of the articles, previously filtered by the inclusion criteria. After this analysis, a set of 21 items was obtained for further study. These were classified according to the level of evidence shown and were ordered according the classification proposed by Lewin, Singleton and Jacobs (2008): ten quantitative studies, five qualitative studies, four systematic reviews of the literature, a literature review and a joint study. Taking into account the level of evidence, five of the items fall into level V, nine into level IV, three into level III and four into the highest level of evidence, level I.

This ILR enabled us to understand the state of the art better and was an important support to develop the NIP, in order to adjust the nursing interventions to the main needs.

In the next phase, we proceeded to create an NIP based on both the emerging scientific evidence of the systematic literature review, and the works by Cardoso's (2011) and Machado (2013), both in the context of intervention programs in nursing.

This programme was developed using the International Classification for Nursing Practice (ICNP) (ICN, 2011) to define the concepts, diagnosis and nursing interventions. We used the Delphi technique (Dalkey, 1969; Justo, 2005) to validate it.

For this, a group of experts composed of 11 nurses with the following characteristics was formed:

- five performed functions in primary health care
- five were teachers in nursing/health schools
- one performed duties in a hospital setting.

Of these, six also researched and studied the issue of FC and have work published in this area.

A face-to-face meeting with the most of the experts was held to present the project, the aims and validate the programme. After creating the initial version of the programme, everyone involved was contacted by email because of its ease, practicality and convenience that this medium provides. Four rounds were conducted in which the members of the group were given two weeks to review each document and reply, followed by 7 days for the researcher to treat the data, after which a new document was sent for consideration. The analysis was carried out using a Likert scale developed for each constituent item of the programme that varied between 1 and 5 points, for which each expert is asked to express their degree of agreement, according to this technique (Cunha, 2007).

In order to achieve consensus on the NIP, we proceeded to analyse the data statistically, namely to find the mean, median, mode and standard deviation.

In the first round, operations whose mean score was less than 4 with a standard deviation greater than 1 and less than 4.5 were eliminated. In the second round, after analysing the various suggestions and opinions presented, a new programme of 90 items was considered. Due to the large number of nursing interventions and difficult workability, we refined the selection. Items with a mean greater than or equal to 4.5, a median of 5 and a standard deviation less than or equal to 1 were selected.

In the third round, it was suggested that we add interventions in the domain of technical assistance for self-care. We chose also to reorganize emotional support in different nursing interventions, keeping the interventions within the scope of a variety of self-care. In this and in the fourth round, we took into account the criteria referred to above, which in the end allowed us to get a high level of consensus around a set of structured nursing interventions.

In the last phase of study, we proceeded to implementing the NIP, in order to enable the FC to provide care to the dependent person and thus facilitate their transition to the role of caregiver. A quasi- experimental study was carried out (Polit, Beck & Hungler, 2004), manipulating one variable (NIP). For this, a pre and post intervention assessment carried out. Data was collected on the same subject before and after the implementation of the programme in order to establish relationships and differences in the variables between the two moments (Fortin, 2006).

The convenience sample (see Table 2), constituted between April 2013 and June 2014 with 70 FC from three Continuous Care Teams (CCTs), as they are the ones referred to by dependent people at home in need of continuous care.

Table 2 - Inclusion and exclusion criteria of the sample

Inclusion Criteria	Exclusion Criteria
Being an informal caregiver	Being a formal caregiver
Providing care to a dependent in at least one Activities of Daily Living	Being the caregiver of a person for requiring palliative care
Taking on the role of responsibility in organizing care	Lack of primary or reference caregiver
Being the primary caregiver, even though there may be more than one informal caregiver	Refusing to take part in the study
Accepting participation in the study over three months	
Belonging to a selected health facility	

In most of these situations, a given family member took up the role of FC for the first time, so the aim of this work is to facilitate the transition to this new role.

We chose these units by geographical proximity, which is essential to the feasibility of work, but also because they include people with different characteristics, rural, urban and mixed.

Five to six home visits (HV) for the most part were carried out to implement the NIP. In addition to these, there were visits by nurses of the different participating health entities. Implementing the NIP lasted an average of three months, associated with the permanent contact with the different CCT teams. The first HV was carried out preferentially in conjunction with the reference nurse, for whom, after signing the informed consent, the data was collected.

We resorted to various instruments to collect this data at the beginning and end of the NIP both for the FC assessment and for the dependent relative. Thus, the MOS SF-36 v2 for the caregiver was filled in (to evaluate the perceived state of health), the QASQI_vr (to review the different types of overload expressed) and the Brief COPE (to determine the most commonly used coping strategies). The Barthel Index and Lawton and Brody scale were filled in for the dependent relative (DR) (to assess their level of disability). In addition to these instruments, a socio-demographic questionnaire was also completed. This provided data that enabled us to contextualize the care process better. For each FC, an individualized plan was formulated, which was then directed to the nursing interventions implemented.

On the second HV, after clarifying the aims they hoped to achieve, the intervention would begin whenever possible by the difficulty or need most highly emphasized by the FC. On this visit, the most commonly used coping strategies were also discussed as well as how they could be enhanced.

On the third, fourth and fifth HV, the work begun in the previous visit was continued and the previously implemented interventions were bolstered, always using positive reinforcement of the work and goals achieved.

In the sixth and final HV, all of the instruments were filled in again in order to evaluate the programme and its impact.

After each visit, the following visit was planned with the caregiver, which would happen 2 - 3 weeks thereafter. The day before each HV a telephone call was made to confirm the visit.

3. RESULTS

From the analysis of the initial IRL, the scientific evidence highlighted a set of needs shown by the FC, which were grouped according to the Theory of Transitions (Meleis, 2010):

- Community and Social resources: the need for family support, the importance of family and interpersonal relationships, social and community support, support groups and the need for breaks in providing care to meet their own social and recreational needs
- Knowledge and preparation: the importance of nurses in imparting knowledge to and training caregivers in instrumental terms; the need for information on the state of health and prognosis; accessibility to health services

- Personal meaning, beliefs and attitudes: the need for psycho-emotional support, empowerment with effective coping strategies for problem-solving and the importance of the family in reducing the emotional burden
- Socio-economic condition: the need for economic support; the need for flexibility of working hours, to reconcile providing care with their professional activity.

In the next phase, and based on the highlighted evidence, we proceeded to adapt the NIP, using a consensus technique. Thus, there were four rounds of appreciation with the collaboration of a group of 11 experts between January and April 2013. We have chosen to consider the level of concordance (mean), the median and standard deviation.

In the first round, the 240 interventions analysed, 82 items were removed after the statistical analysis.

In the second round, after analysing the various suggestions and opinions presented, a new programme of 90 items was considered. At that moment, we honed the selection criteria; 13 items were eliminated, leaving the reduced programme to 77 items.

In the third round, with the changes made, a document with 105 items was submitted for consideration, with 94 interventions in the end.

In the fourth round, this new document was submitted for consideration. Of these, five obtained a mean equal to 4.4, but we decided to maintain them since the data showed that the median value was 5 and the standard deviation was between 0.6 and 0.8, which showed high consensus of opinion around these.

At the end of this stage, a programme of 93 nursing interventions. Their aim is to enhance the transition to the role of FC (see Table 3).

Table 3 - Nursing Intervention Programme: Domains and Dimensions

Domain – Emotional support	Domain – Instrumental support
Dimension	
To promote the Role of Family Caregiver (7 nursing interventions)	To assist in Self-Care: Personal hygiene (13 nursing interventions)
To promote Social Support (9 nursing interventions)	To assist in no Self-Care: Getting ready for the day (5 nursing interventions)
To promote Family Involvement (6 nursing interventions)	To assist in no Self-Care: Dressing and undressing (5 nursing interventions)
To prevent Family Caregiver Stress (18 nursing interventions)	To assist in no Self-Care: Feeding (9 nursing interventions)
	To assist in no Self-Care: Urinary/bowel elimination (9 nursing interventions)
	To assist in no Self-Care: Mobility (14 nursing interventions)

In the final phase of the study, the programme was implemented and 373 HV were conducted, covering a geographical area of 316.37 km². Of the 70 FC in the sample, not all were received all six intervention visits. The duration of these visits also varied:

- First HV: all 70 FC
- Second HV: 69 FC
- Third HV: 66 FC
- Fourth HV: 62 FC
- Fifth HV: 59 FC
- Sixth HV: 47 FC

The average length of the HV was 52 minutes with a minimum of 30 minutes and a maximum of 180 minutes.

The visits by the CCT nurses were also monitored, as they registered all the interventions together with the caregivers, who were taken into consideration.

Regarding the profile of the FC, they were mostly female, average age 60, married, with children, low level of education; most were not employed (retired, unemployed or housewives) (Figueiredo, 2007; Imaginário, 2008; Machado, 2013; Martins, 2006; Sarmiento et al., 2010; Sequeira, 2010; Sequeira, 2013).

The dependent relatives (DR) were highly dependent and needed a great deal of support in their daily activities (Imaginário, 2008; Marques, 2007).

The FC are mainly family members with a direct bond sharing their homes with their DR (Cruz, Loureiro, Silva & Fernandes, 2010; Figueiredo, 2007). Most were first-time caregivers, the affective bond was their main reason to assume the role of caregivers (Martins, 2006; Marques, 2007) and they provided care 12 hours daily, although a considerable number provided 24-hour care. They provided care in all self-care situations in accordance with their DR's limitations and needs, as well as emotional support and regular supervision.

In terms of the main results obtained from the evaluation, there was an improvement in the dimensions of the caregiver's health, with the most significant improvement in the mental health component.

As for overload, there was an improvement in all of the domains, despite the caregivers still highlighting the implications that providing care had on their personal and social lives.

With regard to coping strategies, caregivers have been turning to a number of more diverse strategies more often.

4. DISCUSSION

After analysing the results achieved, good results in terms of health and overload were also found as expressed by the FC, so this work was shown to facilitate the transition to the role of caregiver as well as in performing these functions in the process of providing care.

The comparison between the two evaluations provided data that enabled us to determine the impact of the NIP, demonstrating the importance of this type of instrument and this investigation. Thus, there was an interesting set of changes, namely: in terms of the FC's health, with improvements to their quality of life, as well as their perceived physical and mental health. In terms of the overload manifested, there were significant improvements, particularly in terms of a lower number of references regarding its implications to the FC's personal and social lives. With regard to coping strategies, the FC have been turning to a more diverse range of strategies and implementing them far more often.

Nevertheless, the NIP can still be improved and optimized with the addition of interventions that have not been contemplated (e.g. preventing the risk of pressure sores), as well as its implementation in other contexts, in which a caregiver provides care for a dependent person.

Besides these aspects, this study allowed us not only to get a better perception and knowledge of different processes of care and its context, but also a better understanding of the National Integrated Continuous Care Network and where it may be improved, such as allocating specialized human and material resources better.

Implementing the NIP in later research will allow it to be optimized and become more efficient. The context in which they are to be implemented should be taken into consideration, as well as the transition phase experienced (it is more effective the earlier the intervention begins) and the specific characteristics of each FC and care process experienced.

CONCLUSIONS

We found that an NIP in the domain of emotional and instrumental support is an important tool in working with FC. This work enabled us to obtain an instrument to structure the interventions implemented by the nurses.

We also found that continuity of care is often assured by the FC, despite the inherent sacrifices and demands this role entails. The data obtained in this study are in line with the scientific literature in this field concerning the social and demographic characteristics of FC.

Performing the function of caregiver involves specific requirements and various difficulties; therefore, this type of instrument is particularly important in the context of continuing care. This NIP allows us not only to provide the support requested by the FC in different areas and serve as a guide for the community and social support available, It also provides a set of instrumental skills and knowledge essential to providing care, which will enable improvement.

In short, with this work we were able to minimize the negative effects for the FC associated with the care they provide and to improve its quality, which showed the importance and impact of the NIP.

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